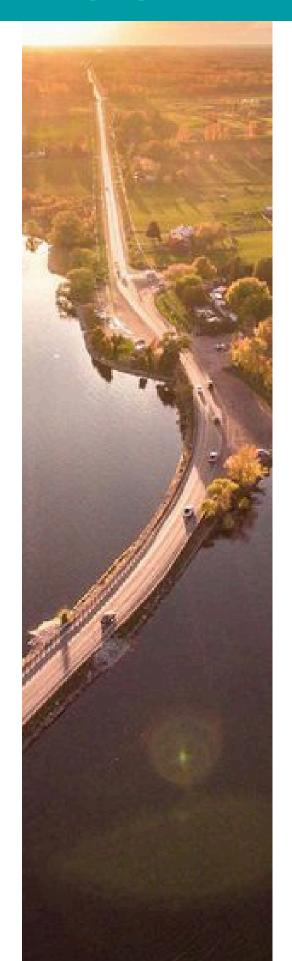




# LIVED EXPERIENCE PARTNER HANDBOOK

Welcome to the Kawartha Lakes Haliburton Ontario Health Team

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## **ABOUT US**

The Kawartha Lakes Haliburton
Ontario Health Team (KLH-OHT) is a
group of healthcare providers and
organizations that are committed to
improving the healthcare experience
in our community.

The KLH-OHT is currently made of lead, partner and supporting organizations in Kawartha Lakes and Haliburton County. We are working together as a team to ensure patients, families and caregivers experience a seamless and supported journey through our healthcare system.

We are creating a strong foundation for collaboration of services, such as increasing access to online appointment booking options, and providing in-home monitoring of chronic diseases. We also aim to increase awareness for residents and patients of available health and community programs and services.

The voices of our community are crucial in guiding the work of the KLH-OHT. We are committed to working with patients, clients, caregivers and family members to shape and improve our local healthcare system.



## THE ROLE OF A LIVED EXPERIENCE PARTNER

#### WHAT IS A LIVED EXPERIENCE PARTNER?

The purpose of a Lived Experience Partner is to improve the patient, client, family, and caregiver experience by serving as a partner to help shape KLH-OHT initiatives. Partners like you represent the voice of patients, clients, families and caregivers and people with lived experience in our community. Your experience, insights and perspectives are invaluable to improving healthcare navigation and support.

Our Lived Experience Partners can be part of the KLH-OHT Lived Experience Advisory and Partnership Committee (LEAP), participate in KLH-OHT working groups, focus groups or one-on-one interviews where they contribute experience and insight to ensure the voice of the community is brought into the decision-making process.



Stories need to be told to create change, and sharing those stories with the right people and repeating them creates change.



Caroline Fenelius-Carpenter
KLH-OHT LEAP Member,
End of Life Doula

#### **ROLES AND RESPONSIBILITIES OF LEAP COMMITTEE MEMBERS:**

- Advise the KLH-OHT on strategic directions, programs, and initiatives from a patient, family, and caregiver perspective.
- Support equity by helping to identify and address barriers to care, especially for underserved, marginalized, or vulnerable populations in Kawartha Lakes and Haliburton.
- Provide input on communications, engagement strategies, and educational materials to ensure they are accessible and patient friendly.
- Collaborate with KLH-OHT partners and working groups to co-design improvements in care pathways, transitions, and integration of services.
- Identify and prioritize emerging patient, caregiver and community member needs and areas where patient voices should be amplified in KLH-OHT decision-making.
- Participate in quality improvement initiatives as appropriate, offering feedback based on lived experience to improve service delivery and health outcomes.
- Foster partnerships between patients, caregivers, and health and community providers to build a more coordinated and compassionate health system.
- Mentor and support fellow LEAP members, particularly during onboarding, by sharing knowledge, experience, and encouragement to build collective capacity and confidence in advocacy and engagement.

## **WORKING GROUPS**

#### LIVED EXPERIENCE AND ADVISORY PARTNERSHIP COMMITTEE

Some of our Lived Experience Partners are members of our Lived Experience Advisory and Partnership (LEAP) Committee. This overarching committee provides a space for Lived Experience Partners to share insights on improving the care and service experience for patients, clients, families, and caregivers in Kawartha Lakes and Haliburton, while helping to shape KLH-OHT programs.

Lived Experience Partners may also choose to participate in planning committees or working groups that align with their lived and living experiences. This ensures that individuals are meaningfully matched to areas of work where their perspectives can have the greatest impact. For example, a partner with experience in heart failure would be invited to join a related working group, while those without that lived experience would be connected to other appropriate areas of focus. Please see below for a list of the various working groups that the KLH-OHT has to offer:



## FRAILTY AND SOCIAL PRESCRIBING WORKING GROUP

This group develops and promotes non-clinical supports, activities, and resources that connect people to their community, improve wellbeing, and address frailty through early identification and coordinated care.



### INTEGRATED CARE WORKING GROUP

This group focuses on key change initiatives that advance standardized, integrated care for CHF and COPD by making the most of current resources and planning for future investments.



## PALLIATIVE CARE WORKING GROUP

This group works to enhance access to community-based palliative care in alignment with the Palliative Care Health Services Delivery Framework.



### DIGITAL AND DATA WORKING GROUP

This group improves ways of sharing patient health records between providers, enhances seamless communication across multiple care settings, and increase digital access to patient health records.



## QUALITY IMPROVEMENT WORKING GROUP

This group identifies opportunities to improve healthcare services, implements best practices, and tracks progress to ensure care in our region is safe, effective, and continuously improving.



### ATTACHMENT STRATEGY WORKING GROUP

This group works to ensure every person in our community is connected with a primary care provider, develops strategies to close attachment gaps, and supports equitable access to care.

# TRAITS AND CHARACTERISTICS



The Kawartha Lakes Haliburton
Ontario Health Team is committed
to providing a safe space for you to
contribute and be respected for
your insight and suggestions.

## CHARACTERISTICS OF A GOOD LIVED EXPERIENCE PARTNER

- Respectful of others and their perspectives
- Comfortable speaking in a group and interacting with others
- Good listener
- Ability to use personal experience constructively
- Ability to see beyond own experience
- Ability to see the big picture
- Demonstrate a non-judgmental and positive attitude
- Work collaboratively with other partners and staff
- Desire to expand knowledge and skills
- Desire to participate in creating meaningful change
- Ability to maintain confidentiality of patient and organizational information

# TALKING ABOUT YOUR EXPERIENCES

As a Lived Experience Partner for the KLH-OHT you may be asked to talk about your experience, to help others understand your care and service experiences and how these experiences have affected you and your family. Doing so can be a powerful way to show the need for specific changes and improvements.

As an advisor, you may be asked to help educate doctors, nurses and other care providers about why it is important to involve patients, clients, caregivers and families in improvement efforts. You may be invited to speak to other patients or family members about becoming a patient/client partner or other opportunities as they may arise.

The KLH-OHT will provide you with training and support for each of these opportunities. You should accept invitations to speak only if you are comfortable with the request.



## BEFORE YOU AGREE TO TALK ABOUT YOUR EXPERIENCE

Before agreeing to speak about your experience in a training, meeting or presentation, get information about what is expected of you and what you can expect.

Ask the following questions:

- When, where and for how long do you want me to speak?
- What do you hope will happen as a result of me talking about my experience?
- Who is the audience? How many people will be there?
- Who else will be speaking?
- Will I be answering audience questions?

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#### PREPARING TO TALK ABOUT YOUR EXPERIENCE

If you have decided to talk about your experience, think about what you want to say and how you want to say it. Some people write down their main points to keep them focused. Before you speak in a meeting or to a group, it also helps to practice. Some people practice in front of a colleague and use their feedback to help clarify the message. Time yourself and see if you are staying within the requested time frame. As you are preparing what you want to say, think about the following questions:

- Why was I asked to talk about my experience?
- What are the key messages I want to share?
- What are the two or three specific points I want the audience to remember?
- What am I willing to share? What is too private to share?

- What examples can I give of when a health care experience went well?
- What examples can I give of things that might have gone better?
- What ideas do I have about how my health care experience could have been improved?



#### TIPS TO KEEP IN MIND

- Only share what you want to share. If you still feel angry or unsettled about a certain situation or event and do not think you can talk about it in a helpful manner, it may be best not to share that part. You can also talk about it with someone you trust. Ask for ideas about how to share that part of your experience in a way in which people will listen.
- Focus on experiences rather than individuals. Avoid using the names of staff or volunteers. If you talk about a facility where you have received care, please do not mention it by name.
- Be prepared for emotional reactions. Expect that some people who
  hear about your experience may be deeply moved. Remember, you
  may feel emotional when you talk about your experience, and it's okay
  to show that emotion.
- Remember you are in control. If people ask you questions and you do not know the answers, it is okay to say so. If you do not want to answer a question, it is okay to say that as well.

#### **COMPASSION FATIGUE**

Compassion fatigue is an important consideration for the Lived Experience Partners. It refers to the emotional and physical exhaustion that can occur from the continuous caregiving and support roles that members often undertake. Recognizing the signs of compassion fatigue is crucial for maintaining the well-being of committee members and ensuring they can continue to provide effective support. The LEAP committee is committed to fostering an environment that acknowledges these challenges and promotes strategies for self-care, peer support, and professional development to mitigate the effects of compassion fatigue.

#### **MENTORSHIP**

Mentoring plays a crucial role in supporting patient families, caregivers, and individuals with lived experience by fostering a nurturing environment for growth and learning. Through mentoring, experienced individuals can share their knowledge and insights, helping others navigate the complexities of caregiving and healthcare systems. This supportive relationship not only enhances the skills and confidence of mentees but also strengthens the community by building networks of trust and collaboration. By prioritizing mentoring, we can ensure that everyone involved feels empowered and equipped to contribute effectively to the goals of the patient family and caregiver community.



## EQUITY, INCLUSION, AND CREATING SAFE SPACES

#### YOUR ROLE AS A LIVED EXPERIENCE PARTNER

As a Lived Experience Partner with the KLH-OHT, you play an essential role in helping shape a more inclusive, respectful, and people-centred health system. A key part of this work is understanding how equity, diversity, inclusion (EDI), and trauma-informed approaches create the foundation for meaningful engagement and how you contribute to that foundation in every space your part of.

KLH-OHT uses a trauma-informed and anti-oppressive approach in all engagement efforts, which helps guide how staff, partners, and lived experience members work together. These principles aren't just for staff to follow, they are tools for everyone, including you, to support safe, inclusive, and respectful environments in LEAP Committee meetings, working groups, or other activities you're involved in.

Here's how you can help bring these principles to life:

#### **SAFETY**

Help create a space, both emotionally and physically, where people feel respected and not judged. This includes being mindful of how we speak to one another, listening with care, and allowing people to share at their own pace. You can also speak up if something feels unsafe or uncomfortable.

#### TRUST AND TRANSPARENCY

Be open and honest in your participation and ask for clarity when needed. Sharing your questions or concerns can help others feel more comfortable doing the same. Your input helps us build trust together as we shape decisions and give feedback.

#### **CHOICE AND AUTONOMY**

You decide when and how you want to participate. Whether you're sharing in a meeting, contributing to a working group, or responding in writing, your comfort and capacity are respected. It's also okay to take a step back when needed, your well-being comes first.

#### **COLLABORATION AND SHARED LEADERSHIP**

You are not just being "consulted"; you are helping lead. Share your insights, offer ideas, and help shape directions. Invite others into the conversation and help ensure everyone has a voice. Your lived experience is a powerful driver of change.

#### **EMPOWERMENT AND INCLUSION**

Recognize your role in helping others feel welcome, especially those who might be new to the table or come from different backgrounds. Encourage a range of voices and experiences, and help reduce power imbalances by being respectful, curious, and supportive.

#### **CULTURAL HUMILITY AND EQUITY**

Be aware that everyone's experience is shaped by factors like race, culture, ability, gender identity, and more. Acknowledge that systems like racism and colonialism still impact people today. We all have a role in creating spaces where people feel seen, heard, and celebrated for who they are.



By being part of the work of the KLH OHT, you are not just sharing your lived experience you are helping create a culture of inclusion, respect, and shared power. In meetings, working groups, and other spaces where you represent lived/living experience, you help set the tone for how we work together. Your voice, presence, and actions help build the kind of health system we all want to see.



#### **UNDERSTANDING UNCONSCIOUS BIAS**

As a partner of the KLH-OHT, you bring your own lived or living experience, which is incredibly valuable in shaping a more inclusive and equitable health system. Part of contributing to safe and respectful spaces is being aware of unconscious bias, something we all have, whether we realize it or not.

#### WHAT IS UNCONSCIOUS BIAS?

Unconscious bias refers to the attitudes or stereotypes that we hold outside of our conscious awareness. These biases can affect how we think about, feel about, and interact with others, often without realizing it. They are shaped by our life experiences, culture, media, education, and the systems we've grown up in.

Unconscious bias isn't about being a "bad person", it's about recognizing that we all carry assumptions that can unintentionally influence how we listen, speak, and make decisions.



#### **EXAMPLES OF UNCONSCIOUS BIAS**

- Making assumptions about someone's abilities based on their age, education, or background.
- Believing one way of communicating or behaving is "normal" or "better" than others.
- Giving more attention or value to people whose experiences seem similar to our own.
- Feeling uncomfortable or skeptical about someone whose identity or perspective is unfamiliar to us.

#### WHY IT MATTERS IN LEAP COMMITTEE WORK

When unconscious bias goes unrecognized, it can lead to exclusion—even in spaces meant to be welcoming. As a LEAP Committee member, being aware of your own biases helps you:

- Truly listen to a range of experiences, even those very different from your own.
- Avoid making assumptions about why someone may act, speak, or feel a certain way.
- Contribute to a culture of respect where all identities and voices are valued equally.
- Support fairer decision-making in group discussions, planning, or evaluations.

#### WHAT YOU CAN DO

- Pause and reflect before reacting, especially if you feel judgment or discomfort arise.
- Stay curious, ask questions, listen deeply, and be open to learning about experiences you haven't lived.
- Challenge stereotypes when you notice them, even in yourself.
- Speak up if you see someone being overlooked or dismissed. Your advocacy helps create safer spaces for all.
- Practice humility, it's okay to get it wrong, and it's powerful to take responsibility, learn, and grow.



Being part of the work of the KLH-OHT means working together with people from many different backgrounds and experiences. By being mindful of unconscious bias, you help ensure this work is grounded in equity, respect, and genuine partnership for everyone involved.



## TRAINING REQUIREMENTS

## ACCESSIBILITY EDUCATION

Accessibility for Ontarians with Disabilities Act (AODA) training provides a foundational understanding of accessibility and how to support people with a range of disabilities—visible, non-visible, physical, cognitive, and mental health-related.

By completing AODA customer service training, participants learn how to communicate respectfully and effectively with individuals of all abilities. For example, when speaking with someone who has a vision impairment, always introduce yourself and speak directly to them—not their service animal. If you need to step away, let them know. For individuals with mobility disabilities, always ask before touching mobility aids or equipment.



Free AODA
Online Training

## **EQUITY, INCLUSION, DIVERSITY, ANTI-RACISM (EIDA-R) EDUCATION**

Understanding and addressing systemic racism is essential to creating inclusive, equitable healthcare systems. This introductory course on Anti-Black Racism, developed by the Toronto Academic Health Science Network, provides an important foundation for recognizing how racism continues to shape experiences in Canada, including within healthcare setting.

Through this training, participants will begin to:

- Recognize the historical and ongoing legacy of Anti-Black Racism in Canada
- Understand how racism operates at individual, institutional, and systemic levels
- Identify and respond to Anti-Black Racism in the workplace



Introduction to Anti-Black Racism

## 2SLGBTQIA+ INCLUSIVE HEALTH

Inclusive healthcare begins with understanding and respecting gender diversity. This introductory course from Trans Care BC offers essential knowledge to help create safe, affirming, and inclusive environments for Two-Spirit, trans, non-binary, and gender-diverse individuals.

Participants will gain a foundational understanding of:

- Key concepts and language related to gender diversity
- The experiences and barriers faced by gender-diverse people in healthcare
- How to support inclusive and respectful interactions



Intro into
Gender Diversity



Cultural safety is essential to providing respectful, informed care that acknowledges the histories, rights, and lived experiences of First Nations, Inuit, and Métis Peoples. This series of foundational courses builds awareness of colonization, systemic barriers, and pathways to reconciliation within healthcare.

Course topics include:

- First Nations, Inuit, and Métis cultures, colonization, and health determinants
- Indigenous history and political governance
- Cultural competence in healthcare settings
- The Truth and Reconciliation Commission of Canada and the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP)



Foundational Courses



#### RECOMMENDED VIDEOS



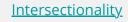






The Paradox of Trauma-Informed Care







## WORKING WITH OTHER ONTARIO HEALTH TEAMS

In partnership with Ontario Health, RISE has launched an online shared space for OHTs to exchange resources and lessons learned, participate in discussions, and collectively solve problems related to the implementation of the OHT model.

There are two online community of practice groups that you may be interested in joining:



#### PATIENT, FAMILY AND CAREGIVER ENGAGEMENT AND PARTNERSHIP

This provincial community of practice is for members of OHTs interested in supporting effective and meaningful patient, family and caregiver (PFC) engagement and partnership. Members may be patient and caregivers already working within OHTs as well as other members of OHTs looking to support patient and caregiver engagement.

Members will access a dedicated space to exchange ideas, tools and resources, deliver and participate in webinars and engage with organizations and experts with experience supporting meaningful patient and caregiver engagement in health and social services across the province. Members will be invited to share their own experiences, resources, implementation challenges and successes, and problem solve together to meet the objectives set out in the quadruple aim.

#### PATIENTS FAMILIES AND CAREGIVERS GROUP

This community of practice is for patients, families and caregivers working with Ontario Health Teams to share resources, tools, and information. This community will also allow members to share their experiences, challenges and successes within their own contexts in a safe space, and to gain feedback and insight from their peers.





If you are interested in joining either of these groups please visit: <a href="https://quorum.hqontario.ca/oht-collaboratives/en-us/">https://quorum.hqontario.ca/oht-collaboratives/en-us/</a>

## RESOURCES AND DOCUMENTS

The following documents will support your role as a Lived Experience Partner with the Kawartha Lakes Haliburton Ontario Health Team. The KLH-OHT will provide you with a digital copy of these documents, and paper copies can be provided upon request.

#### **TERMS OF REFERENCE**

The KLH-OHT LEAP Committee Terms of Reference is a document that outlines the purpose of our Committee, defines responsibilities for the members, and gives criteria on how the group will be composed. It also defines the frequency and expectations of meetings, and how decisions will be made amongst the group.

The Terms of Reference is reviewed and annually in collaboration with LEAP members.

## CONFIDENTIALITY AGREEMENT

To ensure KLH-OHT is in compliance with provincial privacy legislation we ask all lived experience partners to read and sign a confidentiality agreement.

## ORIENTATION POWERPOINT

This presentation will provide more information about the KLH-OHT, our work to date, our partners and how you can contribute.

## COMMON ACRONYMS AND TERMINOLOGY

We are committed to providing information in plain language and avoiding the use of acronyms wherever possible. Occasionally we may reference common acronyms or terminology, and the list below is meant to serve as a resource to help clarify these terms.

**Caredove** - an online health service navigation platform used on the KLH-OHT website

**CKL FHT** - City of Kawartha Lakes Family Health Team

**COPD** - Chronic Obstructive Pulmonary Disease

cQIP - Collaborative Quality Improvement Plan

**EPIC** - digital health record system

FHT - Family Health Team

<u>OHAH</u>- Ontario Health at Home (formerly Home and Community Care Support Services, LHIN and Community Care Access Centres)

<u>Health811</u> - website and phone number to connect to health services in Ontario (formerly Health Connect Ontario)

HH FHT - Haliburton Highlands Family Health Team

**HHHS** - Haliburton Highlands Health Services

KN FHT - Kawartha North Family Health Team

LTC - Long Term Care

MHA - Mental Health and Addiction

**NP** - Nurse Practitioner

**OCO** - Ontario Caregiver Organization

OH - Ontario Health

**OHT** - Ontario Health Team

**OTN** - Ontario Telemedicine Network

PCP - Primary Care Provider

PHIPA - Personal Health Information Protection Act, 2004

**LEAP** - Lived Experience Advisory and Partnership (formerly Patient Family and Caregiver Committee)

PAC - Physician Advisory Council

**RISE** - Rapid Improvement Support and Exchange

**RMH** - Ross Memorial Hospital

## **CONTACT US**

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